Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Winter 99

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Ellie Gunary	**Senior Development Officer**
Angela Ratcliffe	**Development Officer**
Hannah Crown	**Development Officer**
Gina Page	**Administration Officer (Finance)**
Sue Taylor	**Administrative Assistant (Finance)**

NEWSLETTER DEADLINES

Spring	**31 March 2000**
Summer	**30 June 2000**
Autumn	**30 September 2000**
Winter	**31 December 2000**

The Society for Mucopolysaccharide Diseases

46 Woodside Road, Amersham Buckinghamshire HP6 6AJ
Telephone: 01494 434156 Fax: 01494 434252
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The MPS Society is a voluntary support group founded in 1982, which represents from throughout the UK over 900 children and adults suffering from Mucopolysaccharide and Related Diseases, their families, carers and professionals. It is a registered charity entirely supported by voluntary donations and fundraising. It is managed by the members themselves and its aims are as follows:-

To act as a Support Network for those affected by MPS diseases
To bring about more public awareness of MPS
To promote and support research into MPS

The Society offers an information and advocacy service for affected individuals, their families and professionals. At the present time the Society supports two specialist MPS centres at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. It co-ordinates a regional network of Area Families who offer support to MPS families in their own area including organising social events.

The Society also funds research projects at the Christie Hospital, Manchester; Royal Manchester Children's Hospital and the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

There is at present no cure for MPS Diseases but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:-

"CARE TODAY, HOPE TOMORROW"

The photograph on the front page is Father Christmas with Josephine (left) and Francesca (right) who both suffer from Sanfilippo Disease. We all fell in love with this photo which was on the Kembrey family's Christmas card to the MPS Office.

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Deadline for the 2000 Spring Newsletter is 31 March 2000.

DIRECTOR'S REPORT

Welcome to the first MPS Newsletter of this new Millennium. In this edition we are pleased to have so many contributions from MPS families. Please do keep your personal stories, photos and articles of information flowing in. We know from the comments received that stories about individual families are very much appreciated. Do not worry about sending in a 'finished' piece, the Development Team are pleased to help in the presentation of your article.

With this Newsletter you will receive your registration forms for the MPS Conference to be held in Northampton 8 – 10 September 2000. In addition, those living in Scotland and Northern Ireland will receive registration forms for the Scottish MPS Conference to be held in Edinburgh 16th June 2000 and the Northern Ireland MPS Conference to be held in Belfast 12th – 13th May 2000. If any MPS families living outside Scotland and Northern Ireland would like to participate in these conferences please contact the MPS office for a booking form.

Also enclosed with the Newsletter is a booking form for the Share Weekend to be held in Enniskillen, Northern Ireland 9th – 11th June 2000. This Activity Weekend is divided into two. Firstly we are holding an Activity Weekend for those aged 18 years and over who are able minded and are physically disabled by MPS. The second group is an Activity Weekend for families where one or more children under 18 years suffering from any type of MPS or young adults with moderate to severe learning difficulties and suffering from MPS. We hope that families and adult sufferers from all over the UK will attend. Angela Brown is trying to negotiate reduced ferry fares from Stranraer for those wishing to participate from Scotland so do contact the office if you are interested.

In the MPS Office we said goodbye to Sheila Duffy who many of you will know from the organisation of the MPS Conferences. We wish Sheila well in her new post.

Finally, on behalf of all the staff I would like to thank everyone for their kind and seasonable wishes. The MPS office was simply covered with your Christmas cards. We appreciate and understand that Christmas brings mixed blessings for many families affected by MPS. Our thoughts are with you all and may we wish everyone a peaceful New Year.

Christine Lavery – Director

SUPPORT TO FAMILIES OUT OF MPS OFFICE HOURS

There is a new telephone number for families to ring in an emergency out of the MPS Society's office hours. ALL PREVIOUS NUMBERS ARE NO LONGER AVAILABLE.

BETWEEN	**7:00AM**	**-**	**9:00AM**	**MONDAY – FRIDAY**
	5:00PM	**-**	**10:00PM**	**MONDAY – FRIDAY**
	7:00AM	**-**	**10:00PM**	**WEEKENDS/BANK HOLIDAYS**

FAMILIES CAN RING **07712 653258**

to talk to a member of the Development Team.
Hannah Crown, Ellie Gunary, Christine Lavery, Angela Ratcliffe
will be the members of staff answering this phone on a rota basis.

If your call is not answered immediately, please leave a message with your telephone number and your call will be answered as soon as possible.

We appreciate that the cost of calls to a mobile phone may be higher than to a land line and, therefore we will phone families back wherever possible.

NEWS FROM THE MANAGEMENT COMMITTEE

News from the Management Committee November 1999

So much occurs in three months it is sometimes difficult to remember everything. Individual support and advocacy to families is provided on a daily basis with many organised events taking place throughout the year. Thank goodness then for the Management Committee Meetings record. Here is a summary of the decisions taken.

ELECTION OF OFFICERS
Wilma Robins and Sarah Long were elected joint Chairman and Chairperson respectively. Angela Brown was elected Vice Chair. Vince Hayward – Treasurer, Lynne Grandidge, the outgoing Treasurer, was thanked for all her hard work as Treasurer over the last 4 years. Charles O'Toole and Jean Leonard were also co-opted.

POLICIES
The following policies were agreed unanimously. Conduct Policies, Financial Control Policies, Data Protection Policy and Working Time Directive Policy.

HEALTH & SAFETY AUDIT
The Trustees discussed their responsibilities under the current Health and Safety legislation; received a presentation from David Crook of Solutions and considered a draft Health and Safety policy in the light of the recent audit commissioned by Trustees. Further consideration needs to be given, in particular, to risk assessments for all the MPS Society's activities.

THE OFFICE
Y2K COMPUTER AUDIT
The Trustees discussed the Y2K computer audit carried out by Soul Solutions Ltd. It was unanimously agreed to adopt a more secure system complying with the new Data Protection Act 1998 which take effect in March 2000. It was also agreed that the MPS database be updated with more relevant medical information.

FAMILY SUPPORT
The finalised programme of support activities for year 2000 was agreed and is included in this newsletter.

OUT OF HOURS TELEPHONE HELP LINE
In enhancing consistent and equitable support to MPS families throughout the UK, the Trustees agreed that the MPS telephone helpline will provide out of hours emergency support to individual families as follows:

7:00am – 9:00am Weekdays
5:00pm – 10:00pm Weekdays
7:00am – 10:00pm Weekends and Bank Holidays

Outside these hours a message facility will be provided.

SUPPORT NETWORKS
Many families request individual links with another family in similar circumstances to themselves. The Trustees agreed that the networking system was comprehensive and strong. In line with the Data Protection Act written permission is sought from each family whose information is passed on. Families are also advised to add 141 prior to dialling a telephone number if they wish to maintain absolute confidentiality. This service complements the current Area Family Support network.

STAFFING
Recruitment for another Family Support Development Officer is underway. This person will replace Angela Ratcliffe who is currently seconded to the Development Officer post funded by Biomarin and Transkaryotic Therapies Inc. (TKT)

RESEARCH
A further year's funding to Professor Bryan Winchester, Institute of Child Health, for research into 'Expressions of Mutations for Patients with MPS type I, IIIA and IIIB as a prerequisite to Gene Therapy or Enzyme Replacement Therapy' was agreed. Sum awarded £46,085. £30,000 is to come from Jeans for Genes, £10,000 from the Hayward Trust and £6,085 from funds raised by MPS families for research

Wilma Robins & Sarah Long
On behalf of the Trustees

FAMILY NEWS

New Families

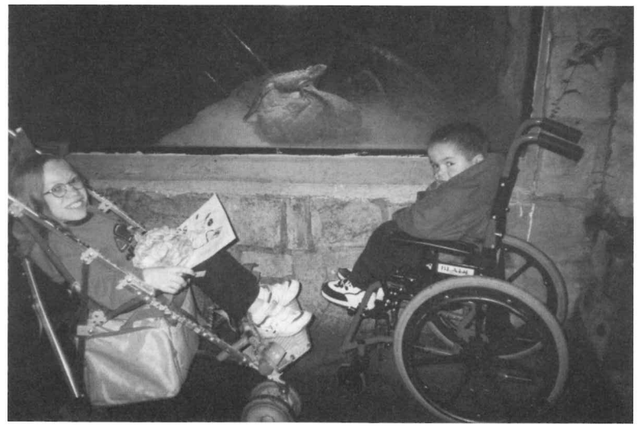
Twelve new families have sought the support of the MPS Society since the last newsletter following a diagnosis of MPS on one or more of their children. This includes the Allen family and the Hall family who have given written permission for their details to be published.

John and Joanne Allen from the West Midlands have a two year old daughter, Bethany, who suffers from Sanfilippo Disease.

Simon and Nicola Hall From Nottinghamshire have a one year old daughter, Jade, who has recently been diagnosed with Hurler disease.

Achievements

Well done to Joanne Evans from Scotland who has been awarded Child of Achievement. Joanne was presented with her award in London on 6th February 2000. Joanne is 13 years old and suffers from Morquio Disease. Joanne is pictured below.



Congratulations to Nora Corcoran on receiving Carer of the Year Award 1999. Nora lives in Southern Ireland and has cared for four children with Hurler Disease.

FAMILY NEWS

Living with a Sanfilippo child

We received this letter from Julie Mcintyre after she read Jo-Anne Adhead's article 'Benjamin has Sanfilippo' in a previous newsletter. We thought it would be of interest to you all, especially the parents of children and young adults with Sanfilippo Disease.

Dear All

I felt moved to write after reading Jo-Anne Adshead's excellent article **"Benjamin has Sanfilippo".**

I thought what a wonderful article it was and it said some very true things and offered such good advice to parents whose children are still in the hyperactive stage. Our daughter Natasha is now 20 and has Sanfilippo Disease. We whole heartedly agree with Joanne's comment "Sanfilippo changed our lives". At the time of diagnosis we thought our lives were ruined. I know now that they are not.

When your child is not sleeping for years and anything that is not nailed down goes flying across the room with yelps of delight it is so very hard to accept and find a 'funny side' to things. I assure you that you will look back on those times and smile at the memory. We now smile at the memories of blackcurrant up the walls and the odd cracked rib when Natasha ran across the room with great gusto for a big hug and a cuddle from Nanny. Everything she did was with energy and untold strength and a joy for life. We are so happy that she enjoyed those years. We now treasure the deep scratch marks on our wall unit where she scraped the wheelchair along it, and lovingly polish them along with the dents from callipers. Natasha would march across the lounge, smiling and singing with a toy in her mouth, turn and back kick the doors twice. Never once or three times, only twice.

She has taught us so much and brought out such love and caring from whoever she meets. She is approaching her 21st birthday, something we never thought we would be able to celebrate. She is no longer the 'round' hyperactive bundle she was, but is now a petite gentle soul. She is more comfortable lying down propped up but still leads a varied day, which she enjoys.

Monday and Friday she goes to her carer's for 5 hours and on Friday she also has hydrotherapy. She has the luxury of her pool session with her own physio who is the physio for the Bracknell Bees Ice Hockey Team. The team of 24 huge muscle bound men have to share him – she has him and the pool all to herself... luxury for a young lady! Tuesday, Wednesday and Thursday she goes out to the Youth Centre, which is a Day Centre for young Adults run by SCOPE. We were nervous, extremely nervous, when she had to leave school at 19, but she has settled well and happily with her new friends.

Natasha has mainly pureed dinners but manages to eat sandwiches and cake on good days. I must say that cake and chocolate profiteroles seem to be accepted with enthusiasm! She does suffer with epilepsy greatly but puts everyone to shame who complains about little pains and colds because she seems to accept everything without complaining. The only time she gets really distressed is if she is 'brewing' a big fit or is hungry.

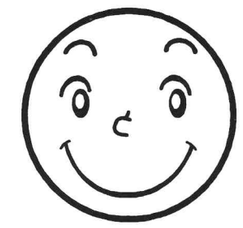
She lights up every ones life if she gives one of her gentle smiles. She offers so much love with a look from her huge brown eyes and when the corners of her mouth lift gently, she can wilt even the biggest and toughest of persons within a split second.

Kirsten, her beloved sister, saw a card with a poem which she brought for her and it says it all:-

FAMILY NEWS

A SMILE

A smile is such a lovely thing,
It brightens up your face,
And when it's gone
It's hard to find
Its secret hiding place.
Yet, still more wonderful it is
Just what a smile can do.
You smile at me, I smile at you.
And then one smile makes two



I close this with the ending of Jo-Anne's letter.

"We are blessed with our children. We do have a good family life – it is just a different one".

Julie Macinyre – Natasha's mum

Thank you Julie for sending us your letter and if any other parent or carer would like to put pen to paper about their experiences living with a child/ adult suffering from MPS we would only be to pleased to receive it.

What Charlie thinks of MPS

Charlie who suffers from Mucolipidosis Type III, thinks that MPS should really stand for '**M**onkey's **P**laying **S**od's in her body!!!!!

FAMILY NEWS

Rail Link Staff help Thomas Birch

Thomas Birch who lives in Kent and suffers from Hunter Diseease had an early Christmas present – a new trike. He had always wanted his own three wheeler and his neighbour Michelle Parish, (who works for the rail link company) decided to enlist the help of her workmates to make his dream come true.

Michelle knew that Sharon, his mother, could not afford to buy him one so Michelle decided to ask the lads at work if they would help.

They collected enough money in three days to buy Thomas the trike, a safety helmet, belt, elbow and knee pads.

Thomas was presented with his new trike by manager Bob Goldring and Rail Link engineeing's representative Jeff Waller.

On behalf of Thomas and his family we would like to thank everyone who donated towards his new trike – He loves it !!

Thomas Birch goes to Lourdes

When the local pub offered to do a fund raising event for Thomas to go to Lourdes, we were all a little apprehensive, as we hadn't even thought about going there. Not holding any great religious beliefs, it would not have been our first choice of a holiday destination, but the landlady of our pub wanted Thomas to go there so her wish was our command

After a few enquiries we discovered that there was a group from the local church which went to Lourdes twice a year. We asked if it would be possible to join their group in October and we were welcomed with open arms. We had booklets given to us to let us see where we would be staying and what the 'Pilgrimage' was all about. We decided to go on this trip with a completely open mind – go with the flow – so to speak.

When we eventually met the people we would be with for the week we were pleasantly surprised. Everyone was so nice. You would expect to be a bit overwhelmed being with 47 other people who go every year but it was lovely. There were three nurses on the trip and they took turns in looking after Thomas so we could do things on our own which was nice.

When we first went down to the Grotto at the Domain, the strangest feeling came over us. It was as if it was meant to be. Very emotional and even Thomas was calmer. It took a lot to try to understand what was going on but that didn't matter. The feeling of love and caring was enormous.

One the first day there was a procession for the Blessing of the Sick and the children were in the front. This was quite amazing to be a part of. We had to walk behind church officials around the Domain and then the blessing was done in the courtyard in front of the Church. That evening they held a candle lit procession which was really beautiful to see and take part in.

During the week we were taken through the story of St. Bernadette and visited different sites where things happened, where she and her family lived and many historic places which are relevant to her life. One day we went on a trip to the Pyrenees and saw the most magnificent scenery.

FAMILY NEWS

Cont/d…

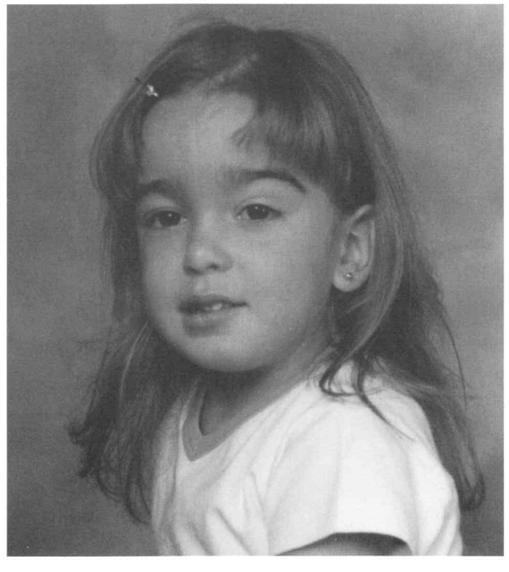
Thomas had lots of fun with all the people taking so much notice of him and there was some older children there who took him off for walks, played football with him and generally kept him amused. They were so good with him and he loved their company.

We are not sure what it was that the three of us got from going to Lourdes but we are sure that we want very much to take Thomas there again. It may not have given us a miracle in curing Thomas, we knew that would never happen, but it seems to have given us something which may help us cope better and improve Thomas' quality of life.. That is all that you can ask for really.

You do not have to be a great believer to get something out of going to Lourdes. It is a beautiful place filled with love and peace and we are so glad that we had the opportunity to go. If you get the chance to visit Lourdes, take it. You will be surprised.

Thomas and Sharon Birch

Pictured right, Thomas at Lourdes



Jordane

Jordane is four years old in March and suffers from Sanfilippo Disease. Jordane goes three full days a week to Kelford School. Her favourite hobbies are watching videos, climbing and chewing! Jordane has a moulded rubber cow and because she chews it, it is called Chew cow and only has one ear. Jordane has a baby sister Brook aged 17 months.

AREA FAMILY CHRISTMAS PARTIES

South West Christmas Party

We held our Christmas Party on Sunday 5th December at Wookey Hole again this year because it proved to be a very spacious and private venue as well as being a fairly central point for most families. Our thanks go to Edward Nowell's sister Mary Ellen for suggesting this venue last year.

This year we hosted the MPS Annual Grand Draw. Doug and Alison Gunnary arrived carrying 3 – 4 black bin bags full of folded raffle tickets (the culmination of hours and days of hard work and sorting). It is very much appreciated.

After we had had our Christmas buffet, we made the draw. Each child was invited to pick a raffle ticket from the big Santa's sack that Jackie Chisling had provided. It proved to be very entertaining especially when some little ones were literally dipped into the bag upside down!

Father Christmas handed out all the Christmas presents with great panache acquired with many years of practical experience!

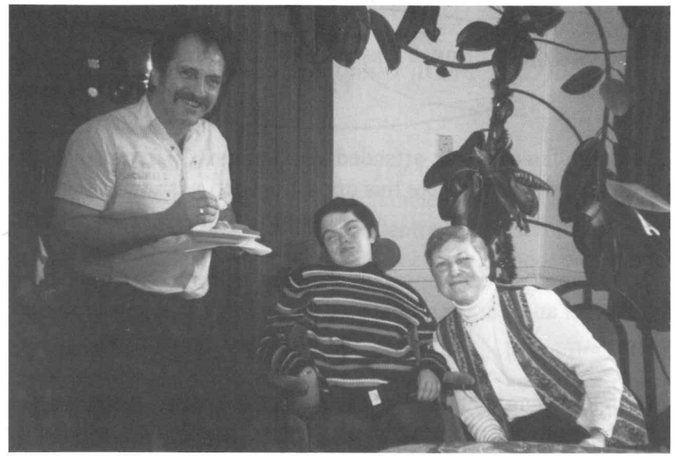
The disco was enjoyed by all, young and old.

As usual, we all had a very enjoyable Christmas Party; we ate, danced, exchanged problems, ideas, joys and sorrows; caught up with each others lives and the progress of our children. We had a raffle on the day and raised £50 for MPS.

Fer Pidden

Josephine & Francesca Kembry with their Mum and Dad

AREA FAMILY CHRISTMAS PARTIES



Annette Puddy with her Mum and Dad – South West Christmas Party

Northern Ireland Christmas Party

The Northern Ireland party was held this year in the Glenavon House Hotel in Cookstown. Twenty-five children and 35 adults were entertained by a two-piece bank 'Rio' who played Christmas songs and requests. Face painting was conducted by Maureen Bruce.

Santa arrived halfway through the show with presents for all the children. This was followed by a lovely buffet. The Magician then arrived, and much to the enjoyment of the children, played tricks and gave each child a modelled balloon.

The afternoon finished with a super ballot with every family winning one or more prizes. It was a lovely afternoon and it was great to meet with everyone again.

Can we give a special mention to Debbie and Mark McAffee and especially their daughter Jade, this was their first MPS Christmas party, and also to mention to both Lily Davis and Gabbie Stewart who were unable to attend due to illness. We wish them well. Thank you to all who contributed to the ballot.

Bernie Drayne

Roma Drayne at the Northern Ireland party

AREA FAMILY CHRISTMAS PARTIES

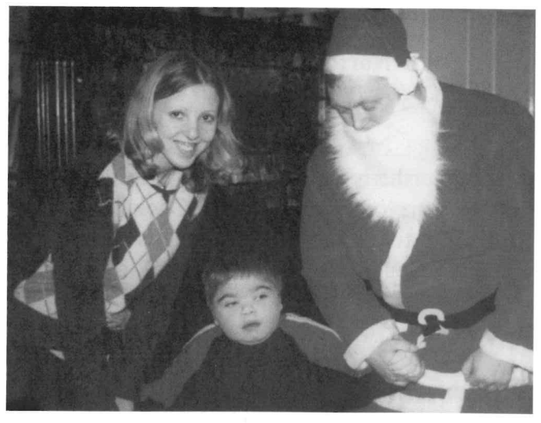
South East Area Christmas Party

We would like to thank the families who attended the Christmas Party at the Cecil Arms Public House in Strood for their support and take this opportunity to wish you all a very healthy and prosperous 2000.

The Cecil Arms put on a super spread for us and made us extremely welcome on the day. We would like to thank Paddy, Rachel and Tara for all the hard work that they put in to making this event as successful as it was.

Also, thanks to Hannah for being there and all the staff at the MPS Office for giving us all the support they do, not only at party time but all year round. - Many thanks.

Sharon, Linda and Thomas Birch



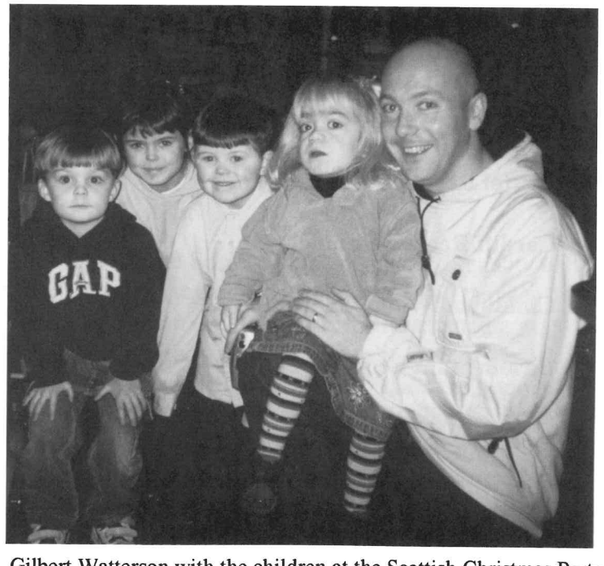
AREA FAMILY CHRISTMAS PARTIES

Yorkshire and East Coast Christmas Party

Becky and Steve Ellis along with their parents and friends helped us put together a wonderful afternoon for the children. After setting out the food the children began with a game of musical chairs followed by eating the food and then pass the parcel. At 2 o'clock Colonel Custard (children's entertainer) came to liven up the day with lots of games, music and tricks for the children and even the adults who he insisted participated. Santa was then visited in the grotto with a present for each. Again the children played pass the parcel and ate bringing the afternoon to an end.

We even had time for an Xmas raffle and £53.00 was raised for MPS.

Barbara and Trevor Rollinson
Area Support Family



Gilbert Watterson with the children at the Scottish Christmas Party

Scottish Christmas Party

The first ever Christmas Party for Scottish MPS families took place at Almond Valley Heritage Centre near Edinburgh on Saturday 11th December. There was fun and games for all the family.

The children loved the soft play area and farm animals and the tractor ride. The highlight of the party was a visit from Father Christmas and presents for the children.

I would like to say thank you to everyone at Almond Valley for helping to make the Scottish MPS Party such a success.

Angela Brown

Aiden Brown at the Scottish Christmas Party

FAMILY SUPPORT ACTIVITIES CALENDAR FOR 2000

DATE	EVENT
Friday 21 January	East Anglia Regional Clinic
Tuesday 15th February	Newcastle Regional Clinic
Thursday 16th March	Bristol Regional Clinic
Friday 17th March	Cardiff Regional Clinic
Friday 12th May	Northern Ireland Regional Clinic (Belfast)
Saturday 13th May	Northern Ireland Day Conference (Belfast)
Friday – Sunday 9th-11th June	Share Weekend– For MPS families and Adults
Friday 16th June	Scotland Day Conference (Edinburgh)
Saturday 17th June	Scotland Regional Clinic (Edinburgh)
Sunday 2nd July	Bereaved Families Day – Childhood Wood
Friday 7th July	Birmingham Regional Clinic
Friday – Sunday 8th-10th September	MPS 18th Weekend Conference
Thursday 19th October	Bristol Regional Clinic
Friday 20th October	Cardiff Regional Clinic
Friday 27th October	Childhood Wood Planting
Friday 8th December	Birmingham Regional Clinic

CLINICS

MPS Clinics

The Society now facilitates specialised MPS Clinics in seven regions throughout the United Kingdom.

East Anglia was held on 21st January 2000.

The following clinics for the year 2000 are:-

Newcastle (Dr. Morris)	15th February
Bristol (Dr. Jardine)	16th March and 19th October
Cardiff (Dr. Shortland)	17th March and 20th October
Belfast (Dr. Stewart)	12th May
Edinburgh (Dr. Robinson)	17th June
Birmingham (Dr. Green)	7th July and 8th December

Arrangements for appointments are made differently for each clinic, however, if you know you need an appointment for any of the clinics please do let Ellie or Hannah know.

A family wishing to attend an MPS specialist clinic in the regions for the first time, must have a referral from their GP or local paediatrician to the paediatrician hosting the clinic (not Dr. Ed Wraith).

Clinic Evaluations

In order for the Society to maintain a high quality of support at the regional outreach clinics all families are now sent an evaluation form after attending a clinic and invited to comment on the level of support offered both by the Society and the regional hospital. We do hope that as many families as possible will take time to complete the form letting us have their views. This is important to the Trustees in their forward planning of the Society's activities.

Birmingham Clinic

I attended the clinic held at Birmingham Children's Hospital and saw seven families. Unfortunately due to Ramadan several families were unable to keep their appointments. This highlighted the need for the professionals organising the clinic to be sensitive to religious festivals.

As it is the policy of Birmingham Children's Hospital not to see patients over the age of 18 years Dr Wraith kindly agreed to see adults suffering from MPS and living in the Birmingham region at an evening clinic held at the Posthouse hotel.

It was lovely to see so many families between the two clinics and I look forward to the next clinic on 7th July 2000.

The Society would like to thank Dr Wraith, Dr Green and Beryl Holmes for all the hard work they put into organising and facilitating this clinic.

Hannah Crown
Development Officer

CONFERENCES

Scotland Day Conference
Saturday 9th October 1999
The Normandy Hotel

On Saturday 9th October the Scottish Conference was held for families and professionals, at the Normandy Hotel near Glasgow airport . The children were also invited to come along and be taken to Glasgow Zoo by volunteers.

In the morning Dr Aitken, Dr Robinson, Dr Wraith and Julie Kelly were the speakers and they covered a variety of topics including 'Medical Emergencies with MPS Children' by Dr. Robinson to the complexities of Enzyme Replacement Therapy by Dr Wraith and Julie Kelly.

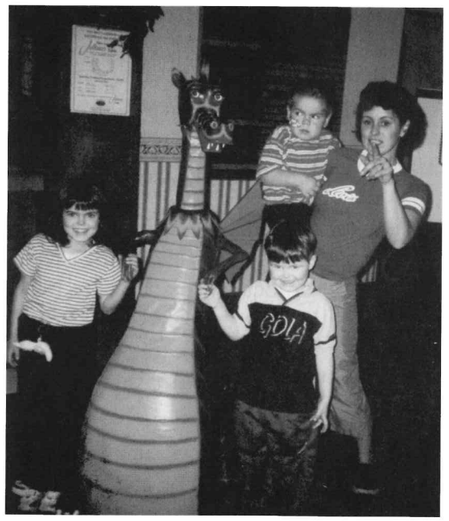
After a buffet lunch we all returned to listen to the following speakers:- Rebecca Howarth from RMCH, Sue Hogg from Rachel House, Angela Brown – Home adaptation, Sarah Long – Facing the future and Ellie Gunary completed the day with an update on the support offered to families through the MPS Society.

At the end of the Conference, when the families along with their children were all enjoying a cup of tea in the foyer, we had an unexpected visit from 'Rodney' the dragon. As you will see from the photograph the children took to him very well. He moved around very quickly and he even held conversations with the children. A big thank you to Rodney for making a special appearance arranged by Sarah Long who had met him the previous day.

It was lovely to meet all the families again and a big thank you to all the professionals who presented their talks. We had a good variety this year and everyone that attended, families as well as professionals, said what a good time that they had had.

On behalf of the MPS Society we would like to thank the volunteers who took the children to the Zoo for the day.

Please remember that the date for the next Scottish Conference is the 23rd June (make a note of it in your new MPS 2000 diary). Booking forms are enclosed with this newsletter.



Angela Brown with her family and 'Rodney'

CONFERENCES

MPS Annual Conference
8-10th September 2000
Stakis Hotel
Northampton

Enclosed with the newsletter you will find booking forms for the annual MPS Conference. To reserve your place, please complete and return the forms to the MPS Society office as soon as possible.

Places are allocated on a first come, first served basis. Please book early to reserve your place. The Conference was oversubscribed this year with families booking later not getting places.

Following Health and Safety legislation the Society now has to complete a risk assessment on all the activities it organises, including meeting the care needs of each child/MPS sufferer who attends. In order to fulfil these legal obligations, except in exceptional circumstances, bookings for the Annual Conference will not be accepted after 30th May 2000.

For those of you who know about booking for the conference before you will find there are additional forms to complete this year. On receipt of your booking form, contact will be made with you by the MPS Society staff to establish your children's needs and ensure all the necessary procedures are fully complied with.

Children's outing at the Scottish Conference

PALLIATIVE CARE

Naomi House

On this sunny October afternoon, I left my children Natalie 19 (Sanfilippo Disease) and Anthony 12 years, in my husband's care and motored off to Naomi House, Children's Hospice near Winchester, for what promised to be an unbelievable treat for rushed off, stressed out mums like myself.

About 20 mums were gathered chatting away, looking more and more relaxed as each minute passed.

The outside speaker was the editor of the local free paper. He enlightened us on the completely computerised, highly automated, up to the minute, state of the art technological wonders of the modern press!

Then, it was the time to queue up for a delightful, soothing manicure. What a divine experience! I ended up with a mauvy pink nail polish complete with glitter.

While this was going on, we had a talk about and sampling of Aromatherpy oils by a very knowledgeable Aromatherapist. She was very nice and helpful. As we were bombarding her with very challenging questions about our children's needs and our complex problems, we were invited to a very appetising and delicious buffet dinner.

The afternoon was rounded off with an Indian Head massage by Stuart who is a new transfer to Naomi House from Little Bridge House – small world.

Non of us had time for a swim, but I don't think it mattered.

As usual the MPS mums were in the majority and almost turned the whole event into a mini MPS gathering.

I left Naomi House feeling relaxed, cared for, pampered and re-energised.

What a lovely thought and initiative!

Having been spoiled once, we are now looking forward to future events and next time I'll make sure I have my camera with me.

All our thanks to all the staff of Naomi House who worked so hard to make this afternoon truly a special one.

Fer Pidden

P.S. Apparently there were lots of grumbles and protests from fathers who felt discriminated against and felt hard done by!

Working with Children's Hospice is a regular part of the MPS Society's role. Christine and Hannah would like to thank the staff at Naomi House Children's Hospice and Ty Hafen Children's Hospice for making them so welcome when they visited recently.

MEMORIALS

We wish to extend our deepest sympathies to the families and friends of:-

Paul Blanchard aged 32 years, who suffered from Hunter.
Adja Fekonja aged 1 year, who suffered from Hurler.
Timothy Hope-Gill aged 18 months who suffered from Hurler.
Grant Pollard aged 27 years who suffered from Hunter.
Bernadette Smythe aged 2 years who suffered from Hurler.
Emma Vigus aged 18 years who suffered from Sanfilippo.
Adam Watt aged 19 years who suffered from Sanfilippo.

Remember

Remember me when I am gone away,
Gone away into the silent land;
When you can no more hold me by the hand,
Nor can I half turn to go/yet turning stay.

Remember me when no more day by day,
You tell me of our future that you planned;
Only remember me; you understand
It will be too late to counsel then or pray.

Yet if you should forget me for a while
And afterwards remember, /do not grieve;
For if the darkness and corruption leave
A vintage of the thoughts/that once I had,
Better by far you should forget and smile
Than that you should remember and be sad.

Christina Rosetti

CHILDHOOD WOOD

The annual sapling planting of the Childhood Wood took place on Friday 29th October 1999.

This year the day was slightly different as we had a light lunch at the Clumber Park Hotel prior to the planting which gave all of the families and guests a chance to meet before going to the wood. The Lord Lieutenant for Nottinghamshire, Sir Andrew Buchanan welcomed all of the guests to Nottingham and then we all made our way to the Childhood Wood. The Chairman of Nottinghamshire County Council Mr Ken Stobbart welcomed everyone to the wood and Paddy Tipping MP, read the poem entitled 'Remember'. It was then time for the families to plant their trees in memory of the children and adults they had lost.

Hannah Crown – Development Officer

Sir Andrew Buchanan planting Mark Simpson's tree.

Children and Adults Remembered

Alice Ruth Beniston
Rebecca Jane Byrom
Emily Grace Hayward
Kai Michael Montgomery
Steven Simms
Mark Anthony Simpson
Liam Prangnell-White

RESEARCH

Embryo Ethics Call

Public opinion is being sought on the ethics of a treatment that allows parents to produce several embryos outside the womb, test them for a genetic disorder, for example MPS, and then implant the non-impaired ones.

Pre-implantation genetic diagnosis (PGD) treatment is currently available at four licensed centres in the UK. An estimated 150 couples have used the £1,000-plus technique since it was introduced in 1990.

PGD can currently only be used by parents with a family history of disorders such as MPS Disease to ensure that they do not have a child with the condition.

Parents can choose whether impaired embryos created during PGD treatment are frozen, donated or "allowed to perish".

James Yeandel, spokesman for the Human Fertilisation and Embryology Authority (HFEA), said: "We feel it is time the public had a say. Not many people have come forward for PGD treatment over the last ten years, but if it does become more popular, then we will have guidelines in place."

Tom Shakespeare, research development officer at the Policy and Ethics Research Institute in Newcastle, said: "This consultation is good in theory, but in practice it needs to be further reaching. It rules out certain implications that will become increasingly important. For example, will this technology be employed over a wider and wider range of cases and will people, other than those affected by a severe impediment, be offered it when having IVF fertility treatment?"

For a copy of the consultation document on PGD, published by the HFEA and the Advisory Committee on genetic Testing, tel: 0207 377 5077 or visit www.hfea.gov.uk. Responses are needed by 31 March 2000.

Hurler Case Studies

I would like to take this opportunity to wish all our families a very happy New Year and to let you know what I am doing now.

I am currently putting together 20 case studies of children with Hurler disease for Dr Emil Kakkis and BioMarin in America. They had been hoping to receive a license and start producing enzyme as a treatment for MPS I at the start of the year. Unfortunately, the Food and Drug Administration (FDA) in America have said that the results from Biomarin's previous trials for Enzyme Replacement Therapy (ERT) require follow up with a further clinical trial. The FDA appear to have suggested that the 10 children treated with enzyme replacement therapy by Dr Kakkis could have made the improvements even if they hadn't received treatment. The FDA will not license ERT until they feel BioMarin have proved that an untreated spontaneous improvement does not happen and that enzyme replacement therapy really does work.

Dr Kakkis is about to start clinical trials on 20 new MPS I patients and I am compiling 20 case studies, so that we can prove that, if left untreated Hurler sufferers do not just start to get better of their own accord.

I have received a lot of help and information from the UK families who are taking part as well as making contact with families in America and Australia who I hope will also be able to contribute to this study. We are also discussing with Europe the possibility of their families also taking part.

Angela Ratcliffe – Development Officer

RESEARCH

Genzyme/Biomarin Press Release 17th November 1999

BioMarin Pharmaceutical Inc. (Nasdaq and Swiss SWX New Market: BMRN) and Genzyme General (Nasdaq: GENZ) today announced that they will conduct a confirmatory phase III clinical trial of *Aldurazyme™ enzyme* replacement therapy for mucopolysaccharidosis -I (MPS-I) prior to seeking marketing approval from the FDA. Following a positive meeting with the FDA yesterday, the companies and the agency agreed to build on the encouraging results of the initial clinical trial of Aldurazyme with additional data supporting the therapeutic benefit of the product.

BioMarin and Genzyme now expect to file a biologics license application (BLA) for Aldurazyme in the United States by the end of next year, ***with market introduction coming in 2001.*** Regulatory filing in Europe will quickly follow the U.S. filing and will be based on results from the confirmatory phase III trial, which will involve centres in both the United States and Europe. The FDA confirmed that Aldurazyme maintains its Fast Track Status.

"MPS-I is a chronic, life-threatening disease, for which no effective treatment options exist. Since inception, the goal of BioMarin's programme for Aldurazyme has been to expeditiously meet the needs of MPS-I patients," said Grant W. Denison, Jr., Chairman and Chief Executive Officer of BioMarin. "We are very pleased with the clinical results we have collected to date, which have exceeded the expectations we had when we began the trial. Building on that foundation, we will continue our work with the FDA on this confirmatory trial".

Henri A. Termeer, Chairman and Chief Executive Officer of Genzyme Corporation, said: "Since we began this programme, we have proceeded with a great sense of urgency, driven by our compassion for MPS-I patients."

"While today's decision extends the timing for the U.S. commercial launch of Aldurazyme, we expect that a confirmatory trial will strengthen our ability to transform the standard of care for MPS-I. By expanding the pool of available clinical data on Aldurazyme, we expect to accelerate acceptance of the product within the health care community. We are confident about. Aldurazyme's potential, and we are working very closely with the FDA to make this product available as soon as possible."

In the initial clinical trial, Aldurazyme was administered on a weekly basis for 52 weeks to 10 patients with MPS-I ranging in age from 5 – 22 years. Patients met both of the primary endpoints prospectively defined in the clinical protocol. Specifically, patients experienced a normalisation of liver size and showed a decrease in the excretion of urinary glycosaminoglycans, the carbohydrate substances that accumulate in patients with MPS-I. The patients who participated in the initial trial continue to receive treatment and are now approaching two years on therapy.

RESEARCH

The confirmatory trial of Aldurazyme will be designed to collect additional data to supplement the positive results obtained in the initial clinical trial of the product. BioMarin and Genzyme are working with the FDA to finalise a protocol for the confirmatory trial. The companies expect trial enrolment to proceed quickly, given the number of MPS-I patients that they have identified through their physician and patient outreach. As in the initial trial of Aldurazyme, patients in the confirmatory trial are expected to represent the full spectrum of severity of MPS-I, including Hurler, Hurler-Scheie, and Scheie syndromes.

As part of the discussions with the FDA, the companies and the agency agreed that it is important to determine a protocol for treating the most severely ill MPS-I patients. BioMarin and Genzyme will work with the FDA to develop this protocol to allow early access to treatment for terminally ill patients. The data from this clinical study is not required for the BLA filing.

BioMarin and Genzyme General formed a joint venture in September 1998 for the development and commercialization of Aldurazyme for the treatment of MPS-I.

BioMarin Pharmaceutical Inc. specialises in the discovery, development and commercialization of carbohydrate enzyme therapeutics. Since inception in 1997, BioMarin has applied its proprietary enzyme technology to the development of products in five therapeutic areas: genetic diseases, burn debridement, fungal infections, male pro-fertility, and inflammation (psoriasis). Glyko, Inc., a BioMarin subsidiary, provides analytical and diagnostic services in the are of carbohydrate biology.

Genzyme General develops and markets therapeutic products and diagnostic products and services. Genzyme General currently has three therapeutic products on the market and a strong pipeline of therapeutic products in development focused on the treatment of rare genetic disorders. A division of the biotechnology company Genzyme Corporation, Genzyme General has its own common stock intended to reflect its value and track its economic performance.

This press release contains forward looking statements regarding our expectations for filing for the biologics license application and market introduction for Aldurazyme; the filing of a regulatory dossier in Europe for Aldurazyme; the locations of, and the protocol for, and the patient population for the confirmatory clinical trial of Aldurazyme; our ability to obtain a compassionate use protocol in that clinical trial; our ability to transform the standard of care for MPS-I; our ability to accelerate market acceptance for Aldurazyme; and the clinical potential of Aldurazyme. Actual results may differ materially from those contained in these forward looking statement as a result of a number of factor, including: the timing and content of submissions to and decisions made by the FDA, the European Commission and other regulatory authorities; enrolment rates and results of clinical trials. The ability to manufacture sufficient quantities of Aldurazyme for development and commercialization activities; the continued funding of the joint venture; decisions made by physician and third payers regarding the use of, and reimbursement for, Aldurazyme; and the actual clinical potential of Aldurazyme.

OVERSEAS MEDICAL INFORMATION

Hydrocephalus and Shunts – an explanation for MPS Parents

P.Lister, Reg. Nurse, Operating Theatre, Australia

(An extract from The Linking Hand across Australia newsletter)

The condition of Hydrocephalus and its treatment cannot readily be explained without first explaining some basic anatomy of the brain.

Anatomy

Deep within the brain lies a series of four fluid filled cavities called Ventricles – two are called the lateral ventricles (left and right) and these connect with the other ventricles called the third ventricle and fourth ventricle. The fourth ventricle is continuous with a channel that runs through the centre of the spinal cord. It also connects with a space around the outside of the brain called the subarachnoid space.

The fluid within these ventricles is called Cerebrospinal fluid (CSF). It acts as a shock absorber cushioning the brain and spinal cord from injury.

CSF is being continually produced by a network of small blood vessels within the lateral ventricles. From the lateral ventricles CSF flows through the two lower ventricles and is then channelled to surround the brain (in the sub-arachnoid space) and spinal cord. The CSF is slowly reabsorbed from the sub-arachnoid space. Around 125 mls of CSF circulates through this system in a normal brain.

Hydrocephalus

If there is any interruption to the flow of CSF within this circuit excessive amounts of fluid will accumulate within the ventricles. This condition is referred to as Hydrocephalus.

As the ventricles enlarge with the excess fluid the brain becomes compressed between the skull and the expanding ventricles. The resulting raised intracranial pressure may cause some or all of the following symptoms:

Headache, irritability, behavioural disturbances, unstable gait, confusion, vomiting, dilated pupils, lethargy, drowsiness and a deterioration of conscious state.

Hydrocephalus can occur in infants, when it is most often associated with a congenital disorder (eg. spina bifida). Meningitis, tumours and intracranial bleeding are other causes of infant hydrocephalus.

Hydrocephalic babies may have a larger than normal head circumference.

The onset of hydrocephalus can be gradual, with a slow progression of symptoms.

In older children and adolescents with gradual hydrocephalus, delayed or early onset of puberty can occur, possibly due to disturbance of the pituitary gland and hypothalamus.

Hydrocephalus is more frequently, however, acute in onset and the neurological deterioration can be quite rapid. Tumours, sub-arachnoid bleeds, a narrowing or occlusion of the duct connecting the third and fourth ventricle and infection are some of the causes of hydrocephalus.

In some cases the cause of ventricular dilation is never established. One theory regarding hydrocephalus in MPS children is that MPS deposits may interfere with the CSF circuit.

Diagnosis of hydrocephalus is made by either a CT scan or MRI of the brain, which will show the enlarged ventricles.

OVERSEAS MEDICAL INFORMATION

Treatment

Treatment is the insertion of a CSF shunt. A shunt is a device that diverts the excess CSF away from the ventricles, thus relieving the compression of the brain. It consists of 2 lengths of silastic tubing (called catheters) and a special valve system which allows CSF to flow in only one direction.

The CSF is usually diverted into the peritoneal cavity where it is slowly reabsorbed. This procedure is called ventriculoperitoneal (or VP) shunt. Alternative CSF diversion sites are the Right atrium (VP shunt) or the pleural cavity in exceptional circumstances.

Procedure

Shunt insertion will be performed under general anaesthetic. The appropriate area of the patients head is shaved and antiseptic is wiped over the operative areas (head, neck, chest and abdomen). In a nutshell a head incision is made, a small circle of skull is removed (called a burr hole) and a catheter is inserted into the lateral ventricle.

A small incision is also made through the abdominal wall. The longer second catheter is threaded under the skin between the abdominal and head wounds. The valve system is seated in the burr hole and connected to each catheter. The value is then stitched in so that it is securely in place. The long catheter tip is placed within the peritoneal cavity. Both wounds are closed.

Shunts are usually positioned on the right side, to avoid interference with the (usually) more dominant left side of the brain.

Possible Post-Operative Complications

1. Infection – shunt insertion requires meticulous sterile technique. An antibiotic is usually administered during the procedure. Should a shunt become infected it is usually removed and a new shunt inserted in a different position.
2. Shunt blockage – a blockage either in the catheters of the valve will produce signs and symptoms of raised intracranial pressure (from brain compression). Neurological deterioration can sometimes occur very rapidly.

The valve system contains a chamber or reservoir that can be compressed by gently pressing the appropriate point on the persons head. Valve compression can sometimes assist in identifying the position of blockage. If the valve or long catheter are obstructed the valve reservoir will not compress. If the short catheter leading to the ventricle is blocked the reservoir can be compressed, thus expressing the fluid, but it will slowly refill. If shunt blockage is suspected the assessing doctor will invariably attempt valve reservoir compression. A CT scan will also usually be ordered – surgery will be required to unblock or replace the obstructed shunt component.

Prior to surgery the neurosurgeon should advise parents of other less common possible complications. While in neurosurgical terms shunt insertion is considered a fairly simple procedure, it is to the parents and patient a big deal and all risks should be discussed and considered. Parents should also be informed of the patients anticipated recovery process and expected length of hospitalisation.

OVERSEAS MEDICAL INFORMATION

CSF Shunts in the Management of Behavioural Problems in Sanfilippo Syndrome

(MPS III) S Robertson and J G Rogers, Victorian Clinical Genetics Service, Royal Children's Hospital Parkville, Victoria 3052
G L Klug, Dept. of Neurosurgery, Royal Children's Hospital, Parkville, Victoria 3052
(An extract from the Linking Hand across Australia Newsletter)

Intermittently raised intracranial pressure is a recognised cause of behaviour disturbance. Frankly hydrocephalus is a frequent occurrence in Hurler syndrome and an occasional complication in Hurler syndrome and Sanfilippo syndrome as well as other Mucopolysaccharidoses. Meningeal thickening secondary to Mucopolysaccharide deposition has been proposed as the mechanism for this phenomenon.

Improved outcome observed in patients with Mucpolysaccharidoses who have undergone bone marrow transplantation has in part been attributed to the reduction in these meningeal deposits which can obstruct CSF flow and or absorption. It is possible that episodes of raised intracranial pressure may be the mechanism that lead to some of the abnormal behaviour in patients with mucopolysaccharidoses. Although ventriculomegaly has been assumed to be a secondary phenomenon due to cerebral atrophy in MPS III and therefore shunting thought not be useful in management we were encouraged to perform CSF shunting in our patients after a positive outcome in another centre. Favourable outcomes using the procedure in patients with Hurler and Hunter syndromes have also been reported. Thioridazine in large doses combined with anti-Parkinsonian agents provides some control over behaviour in most patients with MPS III but it does not always provide sufficient relief from severe problems or screaming episodes.

The experience reported here in a small number of patients with MPS III suggests that CSF shunting may be associated with considerable improvement in behaviour and lessening in the level of agitation. We believe a surgical procedure may be warranted in the treatment of pronounced agitation and hyperactivity in MPS III. The severity of the social and emotional strain that protracted behavioural disturbance brings to bear on care givers, in addition to the suffering attendant on the patients under our care, many of whom have milder phenotypes and are adequately managed with conventional therapy.

In this small series the complications of the procedure were limited to recurrent blockage in one patient and infection of the device necessitating its removal in another. The evolution of a seizure disorder in other patients was probably not attributable to the surgical intervention but instead was consistent with the natural history of MPS III.

It is our impression that CSF shunting, when used in this disorder, does not influence the length of life.

Even though the parents of this group all felt behaviour was substantially improved post CSF shunting, our experience is limited by lack of objective measurements of CSF pressure or comparison in a controlled trial with a matched non-treatment group. The clinical progress of these patients however, when contrasted with the known natural history of this disorder, would indicate that this approach to the treatment of behaviour disturbance in MPS III deserves further study.

OVERSEAS MEDICAL INFORMATION

Definitions:

Intercranial pressure: may be caused by increased cerebral spinal fluid within the ventricles of the brain. May result in, but not limited to, one or more of the following: head-aches, vomiting, visual and mental disturbances.

Hydrocephalus: increased cerebral spinal fluid within the ventricles of the brain.

Meningeal thickening: thickening of the membranes covering the spinal cord and brain.

CSF: abv. For cerebral spinal fluid.

Ventriculomegaly: pertaining to the cavities of the brain (ventricle) abnormally enlarged (megaly). The ventricular spaces look larger on scans secondary to atrophy (wasting) of brain tissue.

Cerebral atrophy: center of the brain associated with memory, learning, reasoning, judgement, intelligence and emotions (cerebrum); decrease in size secondary to "wasting away" (atrophy).

CSF shunting: surgical procedure placing a tube-like structure (shunt) that connects the ventricle(s) of the brain usually to the peritoneum (a cavity in the abdomen) to facilitate drainage.

Thioridazine: (may recognize as Mellaril) treats depression, anxiety, agitation, tension, sleep disturbances and fears.

Anti-Parkinson agents: (may recognize as Cogentin, Parlodel, Sinemet, Larodopa, Eldepryl, Artane) thought to block cholinergic receptors (play a role in transmission of nerve impulses)

NOTE: Never stop medications abruptly without consulting your physician !!

Fiberoptic Intubation and Monitoring of Somatosensory Evoked Potentials in children with MPS

Priv.Doz Dr med Hinnerk Wulf & Ulf Linstedt,Dept. of Anesthesiology and Intensive Care Medicine Hospital
(An extract from the USA MPS newsletter-Courage)

What it is and why it may help some of our children

Endotracheal intubation is necessary during general anaesthesia for maintaining an airway, to administer anaesthetic gases and oxygen, and to aspirate secretions preventing them from entering the lungs. A tube is passed via the mouth or nose into the trachea. Neck hyperextension aids in the proper positioning of the patient so that the body, neck and head are kept in a straight line.

In some MPS patients, particularly MPS I, IV, V and VII, neck hyperextension may put the patient at risk of cervical spine compression which in turn may occlude the conduction pathway to the brain. Prolonged cervical spine compression could precede increased neurological deficits. Other MPS patients I(S), I(HS), II and III , may also present with difficult airways associated with lysosomal storage diseases and benefit from this approach to intubation.

Fiberoptics utilises flexible material of glass or plastic that transmits light along its path and therefore enables the anaesthetist to visualise around sharp curves or corners. Fiberoptics are commonly used for endoscopic procedures where there is a desire to visualise the inside of hollow organs or cavities (joints, bronchi, GI tract).

Waves recorded on a graph signal to the analyser when there is interference with the conduction pathway to the brain – possibly caused by cervical spine compression. It will also indicate occlusion of the airway. In the event this should occur the patient's head can be repositioned to remove the occlusion and the surgery can continue without any harm to the patient. This greatly decreases the chance of increased neurological deficits post operatively.

INFORMATION

Identifying Feeding Problems

Once feeding problems begin to present themselves assessment by a dietician and speech therapist should be carried out on a regular basis.

Feeding problems are usually identified by:

a) Coughing +/- choking episodes when taking food or drinks.
b) Repeated chest infections
c) Meals taking longer on a regular basis
d) Mealtimes becoming "stressful situations"

The recognition of difficulties with feeding does not automatically mean a feeding tube is required. Changes in consistency and texture of foods offered is often the first step along with the use of nutritional supplements.

Council Tax

From April 2000 if a family with a child or adult with a disability pays 'A' band rates they will be able to apply for a reduction of 1/9th of the 'D' band rate. Until now there has been no reduction available for 'A' band.

Thank you to Barbara Arrowsmith for giving this useful information to us – If any other family has some other useful information that they think families should know please write in and tell us.

'Give it a Go' Millennium Awards

A new scheme 'Give it a Go' was launched recently as a partnership between the Millennium Commission and Scope. If you or anyone you might know has a physical, sensory or learning disability combined with the energy and enthusiasm to do something aimed at developing greater self determination or helping the community, then this new scheme could make all the difference.

The scheme promotes the belief that every individual has the right to control his or her own life and share in everyday opportunities, challenges and responsibilities. The scheme is specifically targeted at those with a disability aged over 16 years who have an idea that could help others.

Projects should be completed within one year and can involve a range of activities which include: Learning a new skill and providing a service to the community, making and influencing local change, environmental improvement and disability equality projects that challenge prejudice.

Grants of between £2,000 and £8,000 are available to cover all costs associated with completing a project. The cost of receiving guidance and other support can also be included.

If you think that this scheme is for you or someone in your community, further information can be obtained from a free Helpline on 0800 626216. Information is available in Braille, on tape, and through interpreters for people whose first language is not English.

INFORMATION

Time off for Carers

Carers can take time off work to deal with emergencies involving dependants under a government package of family-friendly policies which has recently come into effect.

The new measures, which fall under the Employment Relations Act 1999, will give all employees the statutory right to take reasonable time off work to sort out unexpected situations without running the risk of dismissal or victimisation.

Two of the situations covered by the policy include when a dependant falls ill or has been involved in an accident or assaulted; and to make longer term care arrangements for a dependant who is ill or injured.

No time limit is set by the government, although in most cases it expects it to be one or two days.

Diana Whitworth, Chief Executive of Carers National Association, said "This is an exciting first step towards proper support for people who combine caring responsibilities with paid work".

Parents adopting a child will be entitled to the same increase in unpaid leave offered to birth parents under the new measures. They will be able to take up to 13 weeks' unpaid leave in the first five years after adoption.

Parents of disabled children receiving Disability Living Allowance will be able to use their 13-week entitlement at any time until the child reaches the age of 18 years.

Could this be of use.....

We have been given a Segufix harness suitable for keeping an active child in a car seat without needing to be permanently fixed into the vehicle.

If you think this would be of use to you, then please contact the MPS Office.

FUNDRAISING

Do you know of anyone needing tennis balls

We have a large supply of clean second hand tennis balls for sale at 10p each.

To avoid postage we can probably distribute them on our visits or through members attending Area Family Days, Clinics and Conferences.

If you are interested, why not give the office a ring?

Foreign Coins and Notes

Please do keep giving us your foreign currency.

Although the amounts may only be small to you, cumulatively the Society can turn these foreign coins and notes into quite big donations to the MPS Society.

FUNDRAISING

The 1999 Chiltern Charity Cycle Ride

A record entry of 30 riders braved steadily deteriorating conditions on Sunday to take part in the fourth annual running of the event. Despite the even increasing rain, there was plenty of enthusiasm from both the ten children and twenty adults who took part, as well as the motorbike mounted video camera crew and those who came just for added moral support. The ride took place over a circular route of 13.2 miles starting (and finishing) in Hyde Heath.

Whilst most cyclists travelled just one circuit, two of the riders managed ten laps between them, Peter Jones (6) and Trevor Knight (4). A mention should also be made for Peter's 12 year-old son, Jason, who managed three laps without any problem.

The two chosen charities to benefit this year are the Imperial Cancer Research Fund and the locally based Society for Mucopolysaccharide Diseases.

I am delighted to report that the ride raised a total of £1069 which is a 12% increase over last year.

Robert Hazell (Organiser)

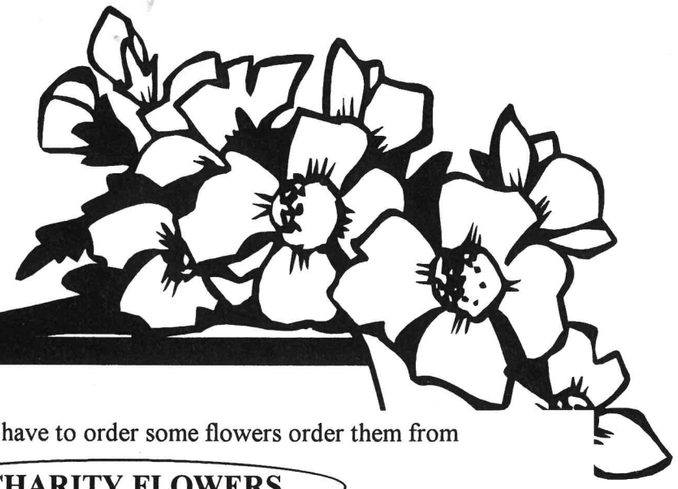
Haddenham Mummers' Play 1999

Please find enclosed a cheque to the value of £346.09, half the sum raised during our winter tours of pubs, clubs and Chinese restaurants, both local and further afield. We hope that you will put this sum towards the research into finding a cure for MPS diseases. *Andy Hardy – Haddenham Mummers*

The Doctor and Father Christmas entertain the troops – Haddenham Mummers Christmas 1999

FUNDRAISING

Up until October 1999 we had received £33.41 commission from Charity Flowers for 1999



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CFD24MPS 20 luxury freesias and posy freesias with greenery = **£14-99**

CFD16MPS 22 stems of luxury carnations, spray carnations with greenery = **£15-99**

CFD43MPS 15 stems of spray carnations, alstromeris and roses with greenery = **£17-49**

CFD32MPS 10 Singapore orchids in mixed shades = **£17-85**

Postal address:
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FUNDRAISING

RESULT OF THE MPS NATIONAL RAFFLE DECEMBER 1999

PRIZE WINNERS

PRIZES		WINNER	TICKET NO.
1st Prize	**£600**	**Glenn McKee**	**41356**
2nd prize	**£300**	**Jean Wilkinson**	**47154**
3rd Prize	**£150**	**Mrs H. Neil**	**57923**
£50 Waitrose Voucher		Abeda Ali	1938
£50 John Lewis Voucher		G. Owbridge	0145
£50 Argos Voucher		Robin Toates	65344
Glass Candle Holder		L. Twaddle	64593
Crystal Parrot		Mr P. Ireland	34478
Grand Tour for 2 at Middlesborough Football Club		C.Littlewood	16930
Thorpe Park Voucher		Belinda	21976
£10 Sainsbury Voucher		Jo Mace	20856
£10 Sainsbury Voucher		'Pete' Sellers	49690
Portfolio Case		Elizabeth Little	47671
Cool Box		Sue Stocker	50062
Golf Umbrella		Jean Towning	58595
Organiser & Pens		Thomas Fiffid	35489
Wooden Photo Album		Jo Britton	23719
Signed Ben Elton Paperback book		Darren Brimble	4077
2 Eurocamp Duffle Bags		Mrs M Connell	40773
2 Eurocamp Duffle Bags & Picnic Mat		M.C. Shooter	54073
Duplo Box		G.J. Holton	6962
Duplo Box		Annette	55702
Duplo Box		A.Shipley	40730
Lego Box		Mr & Mrs B. Wareham	14093
Lego Box		Foster	36238

A BIG thank-you to everyone who sold the MPS Raffle tickets ESPECIALLY to Alison Gunary who volunteered to organise the tickets for a job very well done !! We had a wonderful response again this year – keep up the good work!

2000 MPS NATIONAL RAFFLE

We are now planning the 2000 MPS Raffle and would be grateful to any families who might be able to approach companies/businesses that they work for, to donate a prize.

FUNDRAISING

To keep dry from the snow/rain, please remember that we have those sturdy MPS umbrella's for sale – see photograph below.

Bargain Price = £5.00

Including Postage & Packaging

MPS SWEATSHIRTS

Adult colours new for 2000 are Light Grey and Nay all at £13.50 each.

Children's colours are Light Blue, Red and Light Grey all at £8.00 each.

Postage and Packaging will be an additional £1.25 for one item.
If you require more than one item or any assistance with your order, please contact Sue Taylor or Gina Page.

Thank you to all of you who have purchased the MPS Diaries. We sold out well before Christmas this year. Our apologies to those who ordered too late. In 2000 we will be taking advance orders to assist us in gauging demand for Year 2001 Diaries.

FUNDRAISING

FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events.

Peggy Darper - Stall at Garden party
Mr & Mrs Ballard - Stall at Conference
Bertram Books - Sale of Books
W J Stock - Jig-Saw & Bric-a-Brac Sale
Caversham Folk Festival - Festival
Joan Doyle - Donation in lieu of birthday presents
Tracey Hawkins and participants - Three Peaks Challenge
Dorothy Duckett - Sale of Total Eclipse T-shirts
Mr Meaker - Fundraising
Marianne Stimpson - Webb Ivory Catalogue
Towersey Morris Men - Performances during year
Express Newspapers - Company collection
Yorkshire Dales Walkers - Team Walk
High Wycombe & District Charity Ball Committee - Annual Ball
Valley Farm Caravan park - Raffle
D S Lavender - Proceeds of Catalogue
Marina and Dave - Car Boot Sales
Occasions - Selling spare envelopes
Mrs Barker - Collecting small change
Jenny Hardy - Soup Lunch at Haddenham
The Crosby Hotel - Devils Night & Halloween Weekend
Scottish Police College - Students Fundraising
Carol Westland - Woodley Pagoda Sale & Garden Event
Tony and Pearl O'Niell - Aution of marrow jam
Claire Garthwaite - Dorling Kindersley Book Sale
St Georges Hill Golf Club - Golf Day
MDIS - Sale of obsolete furniture
Trull School of Dancing - Sale of second-hand uniforms
Highfield Special School - Raffle at Area Family Xmas Party
Susan Lowry - Jewellery Sale
Stonelaw high School - Sponsored Swim
Brigid & Una Dawson, Jennifer & Shauna - Ride & Drive Event
Clydebridge Staff - Xmas Dance Collection

Participants of 1999 Chiltern Charity Cycle Ride
Haddenham Mummers - Mummers Play 1999
St Colemans Primary School, Lisburn - Sponsored Colour-In and Spelling
Holy Trinity Nursery School, Lisburn - Sponsored Bounce
Kate Phillips and the Children of the Hillside Players - Xmas Variety Concert
MPS Northern Ireland Xmas Party - Raffle
United Oilseeds Marketing Ltd - Proceeds of Xmas Raffle
Zee Cornish - Sponsored Motor Cylce Ride
1st Woodley Guides - Fashion Show & Pantomime
Jenny Hardy's Mum – sale of marmalade

COLLECTION BOXES

Oversley Mill Services
Catherine Ross
Sue Lowry

DONATIONS

The Society is grateful to the following who made donations

Caroline Wright
Julia Morris
GKN
Mrs Perfect
Jenny Simms
Watling Lodge
UKBS Personnel Services
Blair Foundation
C Humphreys
Benham Charitable Settlement
Mrs Cluckstein Charity Trust
Electrolux Holdings
A G Parfett &Son
Fenwick
Frizington residents
British Nuclear Fuels
Sappi (UK) Ltd
London & Scandinavian Metallurgical Co. Ltd
R F Walker
Joseph Strong Frazer Trust
Gallaher
St Marys Church, Swanage
Mrs Leventis
Jill Franklin Trust
Mars UK
3M United Kingdom plc
Mr Charalambous
Mars Confectionery (UK) Ltd
Jane Crysell
Joanna Wilson
United Assurance Group
Trull School of Dancing
Harrison & Clough Ltd
Mr & Mrs Ingram
Druck Ltd
Mr &Mrs Pollard
William and Mary Riddell
Year 10, Ralph Allen School
Lloyds Bank, Wells

Jardine Lloyd Thompson Group plc
Roxspur Measurement & Control
Berkeley Group plc, Cobham
Tibbett & Britten Group plc
Norwest Hoist Group
Securicor, Sutton
MacKenzie Removals
McCulla Ireland Transport
Christchurch Sunday School, Harrogate
McMillan Publishers Ltd
Henderson Investors
Wessex Water
Scottish Amicable Charities Team
Tioxide Europe
Mr C Harvey
Val Evans
Stone CE Comb. School

IN MEMORY

Albert Waldron
Edward Nowell
Miss Marjorie Butt

AREA SUPPORT FAMILIES

EAST ANGLIA

Julie Thacker — **Tel: 01379 854204**
20 Herolk Way, Harleston, Norfolk. IP20 9QA.

Zelda and Paul Hilton — **Tel: 01406 351524**
17 Stanley Drive, Sutton Bridge, Nr Spalding, Lincolnshire PE12 9XQ

MIDLANDS

Sue and Jeffrey Jodgetts — **Tel: 01827 56363**
6 Godolphin, Tamworth, Staffodshire B79 7UF

Zerina and Sajjad Shah — **Tel: 01902 656147**
37 Lowe Street, Wolverhampton, West Midlands

Doreen and Monty Russell — **Tel: 0121 6864779**
71 Templemore Drive, Great Barr, Birmingham, West Midlands B43 5HF

Lauren Cawthorne who suffers from Hurler Disease in the Christmas mood

AREA SUPPORT FAMILIES

POTTERIES

Lynn and Chris Grandidge — **Tel: 01244 531163**
41 The Boulevard, Boughton, Chester CH4 0SN.

SCOTLAND

Angela and John Brown — **Tel: 01506 495434**
91 Bankton Park West, Livingston, Edinburgh EH54 9BS.

SOUTH-WEST

Fer and Bill Pidden — **Tel: 01373 865117**
5 Westbury Leigh, Westbury, Wiltshire BA13 3SE.

Anne and Gordon Hill — **Tel: 01404 813023****
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX.

WALES

Ann and Michael Kilvert — **Tel: 01686 624387**
Windy Waye, Nantoer, Newtown, Powys SY16 1HH

YORKSHIRE & EAST COAST

Barbara and Trevor Rollinson — **Tel: 01724 341534**
43 Crosby Avenue, Scunthorpe, Humberside DN15 8PA

NORTHERN IRELAND ORGANISING

Margaret Kearney — **Tel: 01265 769565**
7 Leyland Heights, Ballycastle, Co. Antrim, Northern Ireland

Joan Christie, Bernie Drayne, Kieran Houston, John Larkin, Martina Larkin, Debbie McAfee, Michael McCawille, Andrew Sheilds, Alison Shields, Dr. Fiona Stewart.

The following Area Support Families have retired:-

John and Barbara Arrowsmith, Anne Thompson and Mark and Rachel Wheeler.

On behalf of the Society and its' members we wish to extend our thanks and appreciation to these families for all their hard work over many years.

THE MPS SOCIETY BOOKLETS

These booklets are produced on behalf of the MPS Society by parents and doctors drawing on their experience and with reference to medical literature. They are designed to provide guidance for families and professionals caring for an individual suffering from a Mucopolysaccharide Disease.

The Pattern of Inheritance	**@ £1 each ..... copies**
Hurler, Scheie and Hurler/Scheie Disease	**@ £1 each ..... copies**
Hunter Disease	**@ £1 each ..... copies**
Morquio Disease	**@ £1 each ..... copies**
Sanfilippo Disease	**@ £1 each ..... copies**
Maroteaux/Lamy Disease	**@ £1 each ..... copies**
Mucolipidosis II and III	**@ £1 each ..... copies**
Mannosidosis	**@ £1 each ..... copies**
Fucosidosis	**@ £1 each ..... copies**
Is your Child having an Anaesthetic?	**@ £1 each ..... copies**
What to do when a Child dies	**@£1 each.....copies**

I enclose a cheque/ P.O made payable to: The MPS Society for £_____

I require / do not require a receipt.

NAME .....

ADDRESS

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..... **POSTCODE**.....

The Society for
Mucopolysaccharide Diseases

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